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Abstract: BACKGROUND: In this study, we aimed at assessing Inflammatory Bowel Disease patients' needs and current nursing practice to investigate to what extent consensus statements (European Crohn's and Colitis Organization) on the nursing roles in caring for patients with IBD concur with local practice. METHODS: We used a mixed-method convergent design to combine quantitative data prospectively collected in the Swiss IBD cohort study and qualitative data from structured interviews with IBD healthcare experts. Symptoms, quality of life, and anxiety and depression scores were retrieved from physician charts and patient self-reported questionnaires. Descriptive analyses were performed based on quantitative and qualitative data. RESULTS: 230 patients of a single center were included, 60% of patients were males, and median age was 40 (range 18-85). The prevalence of abdominal pain was 42%. Self-reported data were obtained from 75 out of 230 patients. General health was perceived significantly lower compared with the general population ($p < 0.001$). Prevalence of tiredness was 73%; sleep problems, 78%; issues related to work, 20%; sexual constraints, 35%; diarrhea, 67%; being afraid of not finding a bathroom, 42%; depression, 11%; and anxiety symptoms, 23%. According to experts' interviews, the consensus statements are found mostly relevant with many recommendations that are not yet realized in clinical practice. CONCLUSION: Identified prevalence may help clinicians in detecting patients at risk and improve patient management.

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Assessment of Inflammatory Bowel Disease Patient's Needs and Problems from a Nursing Perspective

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Key Words
Inflammatory bowel disease · Nursing roles · Patient needs · Symptom management · Mixed methods

Abstract
Background: In this study, we aimed at assessing Inflammatory Bowel Disease patients' needs and current nursing practice to investigate to what extent consensus statements (European Crohn's and Colitis Organization) on the nursing roles in caring for patients with IBD concur with local practice. ***Methods:*** We used a mixed-method convergent design to combine quantitative data prospectively collected in the Swiss IBD cohort study and qualitative data from structured interviews with IBD healthcare experts. Symptoms, quality of life, and anxiety and depression scores were retrieved from physician charts and patient self-reported questionnaires. Descriptive analyses were performed based on quantitative and qualitative data. ***Results:*** 230 patients of a single center were included, 60% of patients were males, and median age was 40 (range 18–85). The prevalence of abdominal pain was 42%. Self-reported data were obtained from 75 out of 230 patients. General health was perceived significantly lower compared with the general population ($p < 0.001$). Prevalence of tiredness was 73%; sleep problems, 78%; issues related to work, 20%; sexual constraints, 35%; diarrhea, 67%; being afraid of not finding a bathroom, 42%; depression, 11%; and anxiety symptoms, 23%. According to experts' interviews, the consensus statements are found mostly relevant with many recommendations that are not yet realized in clinical practice. ***Conclusion:*** Identified prevalence may help clinicians in detecting patients at risk and improve patient management.

Background

The prevalence of Inflammatory Bowel Disease (IBD) ranges from 0.2 to 0.8% around the world, and still increases in developed and especially developing countries, indicating its emergence as a global disease [1]. IBD starts mainly in young adults; however, most studies described a bimodal distribution with first symptoms and diagnosis increasing in older adults [2]. IBD is characterized by episodes of inflammation, with acute symptoms, including

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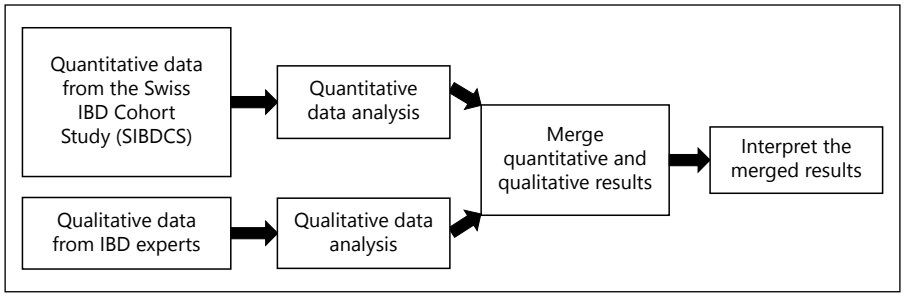

Fig. 1. Mixed-methods convergent design.

bowel pain and diarrhea, and subsequent disease complications such as incontinence, weight loss, bad mood, fatigue, stricture, fistulas, and abscesses. These complications negatively impact the quality of life [3, 4] and work productivity [5] and induce disability, social isolation [6], depression, and anxiety [7–9]. A previous study performed in Switzerland indicated that IBD patients experience a high level of suffering and highlighted that outpatient nursing care could be much more developed to enhance a patient's self-management and quality of life (QoL) [10]. Nurses-European Crohn's & Colitis Organization (N-ECCO) acknowledged that nurses across Europe perform and provide varying roles in caring for patients with IBD. In 2011, they developed the N-ECCO Consensus Statements [11], a consensus on the standard of minimum care that patients with IBD might expect, irrespective of the level of nurse training, title, or country. Caring for IBD patients might include different tasks for different settings such as performing case management, educating patients and following up medication adherence and symptoms management, supporting patients, and helping them in developing self-management strategies [12].

Specialized IBD nurse interventions are often reported as positive and clinically significant [11]. Barlow et al. reported that self-management interventions showed improved outcomes in relation to symptom reporting, psychological well-being, and healthcare resource use, but that education alone was less promising [13]. Optimizing quality of health care by improving information, increasing education and access to psychological analysis was reported as helping the patient understand the disease and to comply with its therapy, increasing quality of life, and reducing depression and anxiety [14]. A pre-post evaluation study that introduced a proactive IBD service found that the disease burden decreased, improving clinical outcomes [15]. A randomized controlled trial introducing a patient-centered approach to chronic disease self-management reported that self-managing patients had greater confidence in being able to cope with their condition, fewer hospital visits, and quality of life was maintained [16]. Most studies highlighted the positive effect of holistic approach of health [3, 4, 17–21], psychosocial approaches [3, 4, 21], and staff training [22] that are reference points for nurse intervention strategies.

Our university hospital center (UHC) is currently evolving a proactive preventive long-term model based on the integrated model of Chronic Care Management [23–25]. To date, there is, however, a lack of information and instruments to assess a patient's need and nursing proactive and preventive long-term care to assess and anticipate changes to a new model of care. In the Swiss health system, the responsibility for the discharge of an IBD inpatient remains a physician-only task; there is no currently existing care continuity structure and care pathways regulating the outpatient follow-up. The question of increasing the nursing staff and improving the continuity of care for chronic patients such as IBD is therefore of main importance, especially in a UHC where many patients are referred to when smaller centers or private practices ask for second opinion or when patients experience a severe acute episode.

The aim of this study was to assess a patient's needs through data already collected in the group of patients included in the Swiss IBD cohort (SIBDC) and seen at the UHC, to assess the relevance of the N-ECCO consensus statement at the UHC, and to evaluate the current practice based on this statement.

Methods

Design

We used a mixed-method convergent design [26] to combine prospective information from a quantitative cohort study (SIBDCS [27]) that investigated a patient's needs and a qualitative study investigating nursing practice (figure 1). Quantitative methods were used to assess self-reported clinical and psychosocial items of IBD

patients, and qualitative methods were used to explore the relevance and the current practice in caring for patients with IBD. We analyzed each source of data separately, reported the results separately, determined the presence of a convergence, differences, or some combination of the two, and reasoned a possible connection in the discussion section.

Data from Patients Included in SIBDCS

We used data collected in the frame of SIBDC. This study was approved by the local ethic committees [27]. Data collection of the SIBDCS has been described elsewhere [27].

All SIBDCS patients are followed up once a year according to the study protocols in order to update the patient's medical record with any changes that have occurred during the previous year. In addition, an annual questionnaire is sent to the patient to collect information about events that have occurred during the previous year and to update the psychosocial situation and clinical evolution. Inclusion criteria for our study were IBD patients of our UHC enrolled in the SIBDC since 2006 and follow-up in our UHC, who came for a medical visit in 2011. Variables of interest were demographic (age, gender, civil status, having own children, time to reach the hospital, education, work capacity) and prospective clinical data (diagnosis, BMI, smoking status, abdominal pain, drug intake, anti TNF-α use (drug suppressing the response to Tumor Necrosis Factor), and number of drugs a day), which were retrieved from SIBDC physician questionnaires. Psychosocial and symptom-related data (except abdominal pain) were assessed from the patient self-reported questionnaire through the short form health survey (SF-36), the Hospital Anxiety and Depression Scale (HADS), and the Inflammatory Bowel Disease Questionnaire (IBDQ). The SF-36 is a patient-reported survey that measures patient health and quality of life [28, 29]. The 36 items are transformed in eight (vitality, physical functioning, bodily pain, general health perceptions, physical role functioning, emotional role functioning, social role functioning, mental health) 0–100 scales, whereby the lower the score the more disability. Further, the SF-36 was divided into two aggregate summary measures: the Physical Component Summary (PCS) and the Mental Component Summary (MCS). All scale questions refer to a 4-week time period [30, 31]. The HADS is a questionnaire of 14 items to determine the levels of anxiety and depression [32]. Each item is scored from 0 to 3, yielding a sum score ranging from 0 to 21 for either anxiety or depression. There are 4 categories: a score from 0 to 7 means no depression, respectively anxiety; 8–10 means mild; 11–14 means moderate; and 14–21 means severe depression, respectively anxiety [33]. The IBDQ is a self-reported quality of life questionnaire with 32 questions grouped into four dimensions: bowel (1, 5, 9, 13, 17, 20, 22, 24, 26, 29), systemic (2, 6, 10, 14, 18), social (4, 8, 12, 16, 28), and emotional (3, 7, 11, 15, 19, 21, 23, 25, 27, 30, 31, 32) [34]. The items are scored on a likert scale, where 1 represents the worst situation and 7 represents the best situation; the total score ranges from 32 to 224 with higher scores representing a better quality of life [35]. A score ≥200 is excellent, from 151 to 199 is good, from 101 to 150 is normal, and ≤100 is poor. A score between 170 and 190 is the value for an IBD patient in the remission phase [36–38]. For this study, we described the total IBDQ score, the four dimension scores, and 8 out of the 32 items (fatigue, unable to attend school or work, loose bowel movements, fear of not finding a bathroom, sleep problems, weight problems, accidental soiling of underpants, limited sexual activity).

Data from Structured Interviews Conducted with Experts

Structured interviews were conducted between August and October 2013 with 4 expert healthcare providers working more than once a week in the current care of IBD patients at our UHC (n = 4: 1 physician, 1 clinical nurse specialist, 1 nurse leader, 1 study nurse). The interviews were conducted by Prisca Stucki-Thür (PST), who used the statement items as structure with the possibility to comment on each item. PST listed all the statements in table format and named them with the N-ECCO nomenclature: Number 2 referred to fundamental IBD nursing tasks, and 3 referred to advanced IBD nursing task. The tasks were categorized from A to J (10 tasks), respectively, from A to M (13 tasks). The description of the tasks can be found elsewhere [11]. Each item was scored in view of relevance and current practice with (1 = relevant statement, respectively, currently followed statement; 0.5 = partially relevant statement, respectively, currently partially followed statement; 0 = not relevant statement, respectively, not currently followed statement). A final score of relevance was calculated corresponding to the sum of experts' answers. All the answers were summed up and divided by the total of answers, resulting in a score between 0 and 1. The nearer the score is to 1, the more relevant the category is. The expert was allowed to comment on each item and at the end of the interview, the expert was asked to mention the three main priorities for IBD nursing for the current and future practice in the UHC. Minutes of the interviews, regarding the comments to the items, were written and the item scoring was directly completed in the prepared table format checklist. During the interview, the expert verified the accuracy of the data, by looking at the computer screen.

Statistical Analysis

Descriptive analysis on sample characteristics included frequencies, proportions, and measure of central tendency (mean, median) and of dispersion (standard deviation, interquartile range) as appropriate. To generalize the data of the 75 psychosocial questionnaire respondents, we compared responders with non-responders for age, gender, diagnosis, abdominal pain, and TNF-α inhibitor therapy use. Age was tested with Wilcox-Mann-Whitney rank test; diagnosis, gender, and anti TNF-α use with Chi-squared test; and abdominal pain with Fisher's exact test.

Quality of life analysis was performed descriptively with median and percentile (total score for the physical component (PCS)), the mental component (MCS), and the 8 dimensions. General population data were used to test the one-sided hypothesis (H0: IBD population will have poorer quality of life scores compared with normal population). From the general population data, the proportion 15.86 was used; this is the mean of the normal population minus 1 standard deviation of the normal population. The statistical significance level was set at 5%. Analyses were performed in SPSS 20 (PASW Statistics, Rel. 18.0.0, IBM Corporation).

Expert statement scorings were summed up to yield relevance and a current practice score for each statement, facilitating the prioritization. Comments to the statement items were reported individually in the minutes of each interview. We used a generic descriptive methodology, based on Sandelowski [39, 40]. This is a well-established qualitative analysis technique to capture the individual statements without interpretation. The analysis was conducted by Hanna Burkhalter (HB) and PST and validated according to the following step: the summarized statements were shown to the four experts separately, asking them if their points of view regarding relevance and current practice are represented.

Table 1. Clinical characteristics of the 230 patients included in the Swiss IDB cohort[&]

	Responders[+] (n = 75) n (%)	Non-responders (n = 155) n (%)	All (230) n (%)	p value
Age (median (IQR))	40 (30–52)	40 (31–50)	40 (25–51)	0.726[∞]
Crohn's disease	43 (57.3)	75 (48.4)	118 (51.3)	0.203[π]
Ulcerative Colitis	32 (42.7)	80 (51.6)	112 (48.7)	
Male	37 (49.3)	100 (64.5)	137 (59.6)	**0.028**[π]
Anti TNF-α use	18 (24)	43 (27.7)	61 (26.5)	0.547[π]
Abdominal pain				
None	40 (53.3)	93 (60.0)	133 (57.8)	
Mild	29 (38.7)	39 (25.2)	68 (29.6)	0.098[#]
Moderate	6 (8.0)	18 (11.6)	24 (10.4)	
Severe	0 (0.0)	5 (3.2)	5 (2.2)	

[&] Clinical characteristics of the 230 patients included in the Swiss IDB cohort, who had a medical visit in 2011. [+] Responders completed a psychosocial questionnaire. Bold means that there is a significant difference between responders and nonresponders. [¥] Difference between responders and nonresponders); [∞] Wilcoxon-Mann-Whitney rank test; [π] Chi-squared; [#] Fisher's exact test.

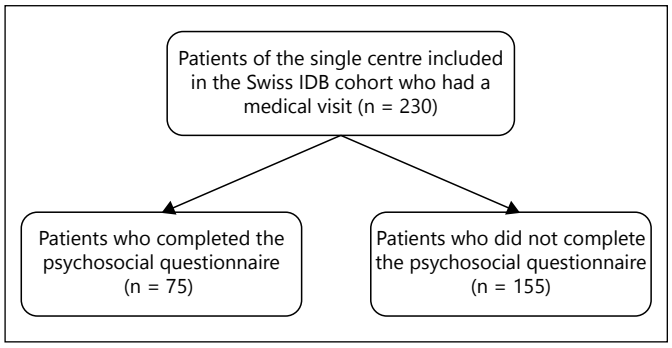

Fig. 2. Flow chart of the sample.

Results

The total number of IBD patients included in our study was 230; psychosocial and symptoms data, other than the abdominal pain, were collected for 75 of those patients (responders) (table 1 and figure 2).

Among the 230 patients, 137 (60%) were males, aged in the median 40 (range: 18–85). There were 112 (49%) UC and 118 (51%) CD. Abdominal pain was reported by 97 (42%) patients. About half of all patients (n = 121) took more than one type drug per day, 142 (61.5%) took the drugs orally, 32 (14%) had intravenous drugs, and 33 (14.5%) had subcutaneous drugs to be injected. Anti TNF-α therapy was provided to 61 (27%) patients. Characteristics of the 75 IBD patients who completed the psychosocial questionnaire are displayed in table 2. Most patients were aged between 31 and 50 (45%), 34 (46%) were married, 43 (57%) had a higher education, 36 (47%) had a full-time job, 17 (23%) had anxiety symptoms (HADS >7), and 8 (11%) had depressive symptomatology (HADS >7).

On comparing both sample sets (responders and the non-responders), they showed no difference in terms of age (p = 0.726), diagnosis (p = 0.203), abdominal pain (p = 0.098), and anti TNF-α use (p = 0.547); however, there were significantly more women among the responders (p = 0.028).

Sociodemographic, Clinical, and Psychosocial Characteristics of the 75 Patients Who Completed the Self-Report Questionnaires

Quality of life analysis showed a median PCS of 53.5 (25th 47.8–75th 56.3 percentile) and a median MCS of 51.3 (25th 44.9–75th 54.7 percentile) (table 3). The dimension of general health perception significantly differed from the standardized general population data (p = 0.001); in fact, 40.5% of IBD patients were below the critical value (mean of the normal population minus 1 standard deviation of the normal population). No statistically significant differences were seen between the scores of poor vitality and poor mental health, as compared with the general population; however, they showed a clear trend toward being impaired in IBD patients (table 3).

The median IBDQ sum score was 189 (25th 169–75th 208 percentile) (table 4). Regarding the selected 8 nurse-specific symptoms of the IBDQ, problems with fatigue were reported by 22 (29%), 8 (13%) were partially unable to attend school or work, 18 (24%) had mostly loose bowel movements, 6 (8%) had fear of not finding a bathroom,

Table 2. Psychosocial-demographic characteristics of the 75 patients who completed the patient self-reported questionnaire

Characteristic	Categories	Percentage (n)
Age	11–20	6.7 (5)
	21–30	21.3 (16)
	31–40	22.7 (17)
	41–50	22.7 (17)
	51–60	17.3 (13)
	61–70	6.7 (5)
	71–80	2.7 (2)
Male gender		49.3 (37)
Civil status	single	43.2 (32)
	married	45.9 (34)
	divorced	10.8 (8)
	missing	0.7 (1)
Having own children		82.2 (62)
Time to reach the hospital	0–30 min	68.0 (51)
	>30 and <60 min	21.3 (16)
	>60 min	8 (6)
	no information	2.7 (2)
Education	no education	1.3 (1)
	compulsory school	14.7 (11)
	apprentice or high school degree	57.3 (43)
	university degree	26.7 (20)
Work capacity	full-time job (28–70 h/week)	47.3 (36)
	part-time job (2–28 h/week)	28.4 (21)
	no information	24.3 (18)
Anxiety	normal (0–7)	77.3 (58)
	mild (8–10)	13.3 (10)
	moderate (11–14)	9.3 (7)
	severe (15–21)	0 (0)
Depression	normal (0–7)	89.3 (67)
	mild (8–10)	4.0 (3)
	moderate (11–14)	4.0 (3)
	severe (15–21)	2.7 (2)
Diagnosis	Crohn's disease	57.3 (43)
	ulcerative colitis	42.7 (32)
Current severity of disease (abdominal pain in CD)	none	48.8 (21)
	mild	39.5 (17)
	moderate	11.6 (5)
	extreme	0 (0)
Current severity of disease (abdominal pain in UC)	none	59.4 (19)
	mild	37.5 (12)
	moderate	3.1 (1)
	extreme	0 (0)
Smoking status	active smoker	20.0 (15)
	non smoker	76.0 (57)
	stopped to smoke in the last year	4.0 (3)
Body mass index	under weight	6.6 (5)
	normal weight	72 (54)
	over weight	14.6 (11)
	extreme overweight	2.7 (2)
	no answer	4 (3)

CD = Crohn's disease; UC = ulcerative colitis.

Table 3. Quality of life (SF-36) among the 75 patients who completed the patient self-reported questionnaire

	Median (IQR)	Mean ± SD	Proportion of patients below critical value*	p value$
Physical component score (PCS)	53.5 (47.8; 56.3)	50.3±9.2	12.5%	0.782
Mental component score (MCS)	51.3 (44.9; 54.7)	48.5±9.7	16.7%	0.426
SF-36 physical function (PF)	95 (90; 100)	89.2±17.7	9.3%	0.939
SF-36 physical role functioning (RF)	100 (75; 100)	78.6±36.7	18.7%	0.253
SF-36 bodily pain (BP)	100 (62; 100)	79.3±27.2	19.2%	0.219
SF-36 general health perception (GH)	57.8 (50; 77)	61.3±9.9	40.5%	<0.001
SF-36 mental health (MH)	76 (60; 84)	71.3±17.2	22.7%	0.053
SF-36 emotional role functioning (RE)	100 (100; 100)	84.9±32.5	16.0%	0.487
SF-36 vitality (VT)	60 (45; 70)	56.4±21.9	22.67%	0.053
SF-36 social role functioning (SF)	100 (75; 100)	83.6±24.1	13.51%	0.710

* Proportion of patients below critical value (critical value is defined as mean of the general population data minus 1 standard deviation of the general population data). $ One-sided p value (H0: IBD proportion > general population proportion) calculated with hypothesized proportion 15.86.

Table 4. Symptoms and complications among the 75 patients who completed the patient self-reported IBD questionnaire

		Median (25th; 75th percentile)	
	IBDQ sum score	189 (169; 208)	
	Bowel symptoms score	61.5 (51; 66)	
	Systemic symptoms score	27.5 (23; 30)	
	Emotional function score	71.0 (62; 78)	
	Social function score	34.0 (31; 35)	
Nr	Single care relevant questions		Percentage (n)
2	How often has the feeling of fatigue or of being tired and worn out been a problem for you during the last 2 weeks?	All of the time	2.68 (2)
		Most of the time	8.00 (6)
		A good bit of the time	18.67 (14)
		Some of the time	13.33 (10)
		A little of the time	14.67 (11)
		Hardly any of the time	25.33 (19)
		None of the time	17.33 (13)
4	How often during the last 2 weeks have you been unable to attend school or work because of your bowel problem?	All of the time	4.05 (3)
		Most of the time	4.05 (3)
		A good bit of the time	5.41 (4)
		Some of the time	2.70 (2)
		A little of the time	4.05 (3)
		Hardly any time	0 (0)
		None of the time	79.73 (59)
		Missings	0.75 (1)
5	How often during the last 2 weeks have your bowel movements been loose?	All of the time	8.00 (6)
		Most of the time	5.33 (4)
		A good bit of the time	10.67 (8)
		Some of the time	8.00 (6)
		A little of the time	12.00 (9)
		Hardly any time	22.67 (17)
		None of the time	33.33 (25)
11	How often during the last 2 weeks have you been troubled because of fear of not finding a bathroom?	All of the time	2.70 (2)
		Most of the time	2.70 (2)
		A good bit of the time	2.70 (2)
		Some of the time	5.41 (4)
		A little of the time	6.76 (5)
		Hardly any time	21.62 (16)
		None of the time	58.11 (43)
		Missings	0.75 (1)
14	How often during the last two weeks have you had problems getting a good night's sleep, or been troubled by waking up during the night?	All of the time	8.11 (6)
		Most of the time	8.11 (6)
		A good bit of the time	9.46 (7)
		Some of the time	24.32 (18)
		A little of the time	10.81 (8)
		Hardly any of the time	17.57 (13)
		None of the time	21.62 (16)
		Missings	0.75 (1)
18	Overall, in the last 2 weeks, how much of a problem have you had maintaining or getting to the weight you would like to be?	No trouble	57.53 (42)
		Hardly any trouble	15.07 (11)
		A little trouble	6.85 (5)
		Some trouble	10.96 (8)
		A significant problem	5.48 (4)
		A big problem	2.74 (2)
		A major problem	1.37 (1)
		Missings	1.50 (2)

Table 4. (continued)

Nr	Single care relevant questions		Percentage (n)
26	How often during the last 2 weeks have you been troubled by accidental soiling of your underpants?	All of the time	0 (0)
		Most of the time	0 (0)
		A good bit of the time	2.70 (2)
		Some of the time	4.05 (3)
		A little of the time	1.35 (1)
		Hardly any time	12.16 (9)
		None of the time	79.73 (59)
		Missings	0.75 (1)
28	To what extent has your bowel problem limited sexual activity during the last 2 weeks?	No sex as a result of my bowel problem	4.23 (3)
		Major limitation as a result of my bowel problem	5.63 (3)
		Moderate limitations as a result of my bowel problem	2.82 (2)
		Some limitations as a result of my bowel problem	2.82 (2)
		A little limitations as a result of my bowel problem	7.04 (5)
		Hardly any limitations as a result of my bowel problem	12.68 (9)
		No limitations as a result of my bowel problem	64.79 (46)
		Missings	3.75 (5)

Nr = Number of the item belonging to the self-reported IBD questionnaire.

19 (26%) had sleep problems, 7 (9%) had weight problems, 2 (3%) were troubled by accidental soiling of underpants, and 8 (13%) had limited sexual activity caused by bowel problems (table 4).

Relevance of Nursing Practice, as Compared with N-ECCO Consensus Statements

The four experts assessed the relevance of the N-ECCO consensus statement at the UHC and evaluated the current practice based on this statement. The categories named with the N-ECCO nomenclature [11] with a key word are shown in Appendix 1. In the first row, we first listed the scores for the relevance and in the next row, we listed the scores for the current practice. Appendix 2 shows the priorities suggested by the experts. The four experts judged eight of the 10 fundamental IBD nursing tasks as very relevant (range 0.83–1.00). One item 2F (patients and careers may require ongoing support and education from nurses regarding nutrition and especially in specific situations such as structuring disease, or after surgery) was not relevant at all (score 0.50). The current practice scores showed values below 0.5 for 6 categories: The C items (advocacy for IBD patients), E (in fistulating IBD patients, ensuring patient comfort, protecting skin integrity, and managing complications), F (awareness of nutritional issues to ensure management – support and education), G (be aware of impact of incontinence on quality of life – tailor interventions), H (identifying problems regarding sexual function – support and refer to specialists), and I (identify fatigue – help patients to manage). The scores of the advances in IBD nursing categories were relevant (range 0.83–1.00). The current practice scores showed values below 0.5, mostly a score of 0 (no current practice in this regard).

Discussion

This study was performed to assess a patient's needs through data already collected in the group of patients included in the Swiss IBD cohort (SIBDC) and seen at the UHC, to assess the relevance of the N-ECCO consensus statement at the UHC, and to evaluate the current practice based on this statement. Our main findings were that patients coming to the UHC for a follow-up check have a high prevalence of abdominal pain (42%), anxiety symptoms (23%), and depressive symptomatology (11%). Furthermore, 40% of IBD patients were below the critical value compared with the general population regarding general health perceptions. These facts highlight the need to assess more frequently those symptoms for each patient or shorten the follow-up intervals when a screening questionnaire is positive. Fatigue (29%), sleep problems (26%), and having loose bowel movements (24%) concerned a quarter of the sample, highlighting a need for intervention and structured follow-ups. The scored relevance and the current practice of fundamental and advanced IBD nursing tasks in the UHC showed a large discrepancy. The

main results reflect the deficiently structured current practice of the fundamental nursing tasks and the absence of advanced nursing tasks such as screening, assessing, and follow-up of the interventions in IBD patients.

We found that 42% of the patients reported abdominal pain in the past two weeks. This score is high and shows a clear topic that could be optimized in our follow-up care. Current drug treatments for IBD patients have the objective to induce and maintain the patient in remission, control symptoms, and ameliorate the disease's secondary effects [41]. Often, not all symptoms can be controlled (e.g.: diarrhea and rectal bleeding, abdominal pain, cramps, and joint pain), as the disease is characterized by chronic recurrent ulceration of the bowels. However, it is known that IBD patients suffering from pain have decreased health related quality of life [42]. An optimization of the follow-up pain management would include more than a regular screening tool assessing abdominal pain; indeed, that would mean a multifactorial pain cause assessment (including joint pains [43, 44]) with the assessment of psychosocial consequences, that is, stress and quality of life. Pain has mostly multifactorial etiologies; therefore, it is advised to treat IBD patients with individualized plans [45] that might include supportive therapy such as cognitive behavioral, stress management, coping, acupuncture and nerve blocks, and antidepressants [45]. Schirbel et.al stress the underestimation of pain intensity often done by healthcare providers during follow-up care [42]. Clinical anxiety (HADS >10) (9.3%) and depression scores (HADS >10) in our patient sample (6.7%) were very low compared with those of a Spanish study including 875 IBD patients, reporting that 10.5% had clinical anxiety and 20.1% had depression [46]. Our prevalence must be considered carefully, as the sample was small. In an English sample, symptoms of anxiety were only slightly higher (25%) compared with our prevalence of 23% (HADS >7) and symptoms of depression were higher (15%) compared with our prevalence of 11% (HADS >7) [47].

Most patients have an average quality of life, suggesting that they have integrated relatively well their illness into their life. There was only a significant difference in the general health perception. Our general health perception score was similar to that of a Swedish IBD sample 61.2 ± 10.3 in CD and 64.4 ± 9.9 in UC [48]. The component scores reported in our study are similar to those in Norwegian [17] and UK [48] IBD patients and are higher compared with those in a Scandinavian study including only distressed IBD patients, where the component vitality was the lowest followed by health perception [49]. The sum score of the IBDQ-32 [50] was similar to the scores in a Dutch cohort [51] and a Norwegian cohort [17]. We had a high prevalence of fatigue (29%); this is in line with a study reporting a prevalence of 39% [52] and all the efforts put into developing a scale to measure fatigue in IBD patients [53]. Sleep problems seem to be an emerging issue in IBD patients (50% with inactive IBD reported sleep problems) [54] and confirm our high prevalence derived only from a single item (26%). Having loose bowel movements (24%) concerned a quarter of the sample; this is a very vague prevalence, as not all diarrheas are the same [55]. The World Gastroenterology Organization (WGO) recommends assessment for diarrhea, constipation, rectal bleeding, severe urgency, tenesmus, abdominal cramping, pain, nausea, and vomiting [56].

The N-ECCO CS was judged very relevant for our UHC; however, the nutrition and stoma/fistula statements were categorized as irrelevant. In the UHC, we have an institutionalized nutritionist and fistula nurse who works in a counselling manner and, therefore, gastroenterology nurses caring for IBD patients do not specialize in nutrition and stoma care. Further, incontinence was regarded as a problem that should be solved at home, as the UHC does not support different kinds of material, but only one size for all material. Further, sexuality was considered a taboo topic that should not be addressed in an ambulatory care room with multiple persons. Finally, fatigue was considered an unproblematic issue. The advanced nursing tasks were scored relevant; however, none is performed.

In 2012, 192 European nurses who attended the N-ECCO Meeting and School participated in a survey that consisted of 11 questions about the role and responsibility of nurses in the care of patients with inflammatory bowel disease [12]. This study reported that most nurses (75%) assessed patients over the telephone, 32% in research, 43% within the endoscopy unit, and 45% assessed patients in wards. More than eighty percent (82%) of nurses provided telephone contact for patients, 81% coordinated patients' therapies and of this, 63% also directly administered these therapies, 22% performed endoscopic procedures, and 70% were involved in providing patient education [12].

To follow the N-ECCO standard of minimum care [11] in our UHC would mean to invest in a proactive care model; for example, to invest in the creation of a nurse-led walk-in clinic with telephone consulting that organizes individualized follow-up schedules to follow up on pain, anxiety, depression, and perceived general health issues and to inform, counsel, and educate IBD patients on their needs. The main focus would be on IBD patients

at high risk for adverse events with polypharmacy, complex therapy regimen, high vulnerability, and foreign languages. This nurse-led walk-in clinic would follow the N-ECCO CS [11] and develop guidelines regulating the intervention range, the scope of the nurse, the responsibility of the physician, and the inter-professional multidisciplinary exchange rounds [57].

Finally, the Swiss healthcare system should as well change the payment policy to support the start-up of proactive follow-up initiatives. Taking a proactive preventive approach requires some up-front investment and a long-term vision [58]. Addressing symptoms and risk factors may not result in immediate changes, but a long-term perspective toward managing IBD manifestation is required [58]. Healthcare teams avoiding hospital admission through proactive prophylaxis should be rewarded, and hospitals profiting from unnecessary readmissions should be banned [59].

Experts mentioned in their priority list (Appendix 2) the need to introduce a nurse led drop-in IBD center, to structure the follow-up schedule, to introduce a proactive system, and to have more counseling rooms for undisturbed counseling and education sequences. The implementation of an advanced practice nurse for IBD patients to provide follow-up appointments, rapid access for patients with disease exacerbation, respond to patients' phone calls, monitor medication, educate, counsel, and serve as a liaison in the multidisciplinary team would empower the patients in their chronic disease. The consequence would be the development of role competencies and standards for practice.

Limitations and Future Research

This study had a convergent mixed-methods design. We only collected the qualitative data and used the prospective SIBDCS data as a complement. Usually, the purpose of a convergent design is to collect purposefully different but complementary data on the same topic using both quantitative and qualitative methods [26]. Therefore, our design is not perfectly in line with this definition. Nevertheless, the integration of these two study results has provided an understanding of the current nursing quality and nursing role in caring for IBD patients in our UHC. Unfortunately, only 75 patients answered the psychosocial questionnaire; for future studies and cohorts, the patient's burden and time to fill in questionnaires should be considered.

Future research in our UHC is needed to demonstrate that IBD nurses help improve desired health outcomes in patients. In addition, the advanced IBD nursing role has to be integrated and established in order to assess their impact on the care and management of IBD patients and, finally, the advanced IBD nurse has to demonstrate the relevance of her role in caring for patients with IBD.

Conclusion

Our results have provided an understanding of the patients' needs, problems and the current nursing role in caring for IBD patients in our UHC. According to experts' interviews, the consensus statements are found mostly relevant (for the general and for the advanced nursing practice), with most items not yet carried out. To improve current nursing practice, especially pain, anxiety, depression, and general health perception should be addressed.

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Appendix 1

Qualitative Analysis of Expert Interviews

N-ECCO statement	Score relevance	Score current practice	Summarized expert comments
2A (having basic IBD knowledge)	0.91	0.53	The knowledge of study nurses and ward nurses was estimated as high; however, the knowledge of the ambulatory nurses was rated insufficient. The IBD care path is unclear about the responsibilities of patient education (e.g., patient needing a subcutaneous shot). Often the study nurse assumes the responsibility. Further a patient needing an ambulatory therapy cannot be served immediately; he receives a new appointment from the ambulatory care nurse.
2B (awareness of the extra-physical impact of the illness, key concerns…)	1.00	0.70	The issues, symptoms and worries expressed by patients are not systematically noted on patients chart for out-patients. In-patients receive a nurse assessment and daily evaluation. Nurses complain about a lack of human and system resources. In addition, an in-depth assessment is not feasible as there are no rooms for an interview (there is only the ambulatory room with all the patients waiting). Finally, one expert complained that a random nursing assessment is leading to increased and uncoordinated calls to the physician.
2C (advocacy for IBD patients)	0.91	0.40	IBD nurses do not perceive to have the task of speaking up for the IBD patient. As there is no protection of privacy in the ambulatory care room, nurses do not ask. Privacy is guaranteed in the physician conversation; therefore nurses encourage patients to speak up for themselves. In spite of that, patients tell about their lives (symptoms, thoughts…) and active nurses declared a need for a structured nurse chart to note patient's report. Wound, ostomy, continence… care should be involved in an easier way.
2D (communication)	0.94	0.53	The expert highlights a lack of clarity regarding who is responsible for which information delivery. Information and education session are mostly bound to a drug or an acute symptom or illness. It is not clear who assumes the responsibility for the communication after the diagnosis confirmation, diagnostic results, comorbidities or surgery. The IBD out patient is in the ambulatory care room for a very short time and there is not time for supportive talks. There is no regular evaluation of the professional communication of nurses. There is currently no global brochure including symptoms and quality-of-life issues.
2E (care for fistulating IBD patients)	0.92	0.21	The counselling of fistulas is the task of the ostomy nurse. The ambulatory care nurses do not feel responsible for the skin care or protection. Currently, the physicians have to detect the problem and involve the stoma nurse.
2F (nutritional issues)	0.50	0.21	Experts reported that nurses should have basic knowledge about nutritional issues; however, they should not educate or advice as this is the task of the nutritionist. The physician has to evaluate the risk and if needed notify the nutritionist.
2G (incontinence)	0.95	0.26	The ambulatory nurses do not assess for incontinence. Nurses think that this issue should be taken up by the physician in charge during the consultation, where more privacy is guaranteed. In addition, there is a severe problem in the hospital of available toilets in case of diarrhea. Nobody seems to be responsible for this topic. Pharmacies and online stores provide patients with samples and help them to choose the right size. 'One size for all' incontinence material is available on the ward – however there is no incontinence counselling available at the hospital
2H (sexuality)	0.00	0.00	Sexuality is a taboo topic. Nurses do not talk as they feel not enough educated and they think that they are not competent to do so.
2I (fatigue)	1.00	0.36	Tiredness and fatigue are seldom addressed by nurses and rarely picked out as a theme. Often fatigue is addressed by the physician in case the ferritin level is low.

Appendix 1 (continued)

N-ECCO statement	Score relevance	Score current practice	Summarized expert comments
2J (pain management)	1.00	0.62	Nurses are not allowed to prescribe drugs. Study Nurses deliver pain drugs in the acute situation; however, ambulatory care nurses only deliver a pain drug if it is prescribed. For acute pain in the ambulatory care room, the IBD nurse has to call the physician for a prescription. For a new prescription the ambulatory nurses have to give the patient a new appointment with the physician. A long-term pain management is nearly never discussed with the patient, even as it is considered very important.
Sum score	0.81	0.38	
3A (autonomous clinical expert)	0.98	0.00	Currently, there is no advanced IBD Nurse. Assessment and provision of evidence-based care planning, treatment evaluation, and who provides practical information, education and emotional support for patients with IBD is partially done by IBD nurses. The system could be improved by an advanced practice nurse supervising the IBD care process. However, the interdisciplinary collaboration must first be improved.
3B (education, research, service development and leadership)	1.00	0.50	In the future an ANP is expected to enhance communication and team skills to improve the interdisciplinary collaboration. This nurse must bring a master's degree and an advanced training in IBD. Sadly there is no advanced training in IBD in Switzerland. Therefore, this nurse must at least have a multi-year experience in IBD care.
3C (part of multidisciplinary team)	1.00	0.00	No comments given by the experts.
3D (to enable and empower the patient)	1.00	0.00	Education is partly done by the ambulatory care team, study nurses or on the ward.
3E (expert knowledge)	1.00	0.00	No comments given by the experts.
3F (conception, pregnancy)	1.00	0.00	Health promotion is needed.
3G (adolescent patients)	1.00	0.00	There is one nurse caring for those transitioning from the children's hospital to the adult ward. A standardized transition guideline or concept is needed.
3H (adhering to guidelines)	0.83	0.33	The safeguarding that appropriate screening and identification of any contraindications to therapy are identified is a shared job between the study nurse and physicians. This is a team work. The final responsibility is carried by the physician. There is no document for nurses to note the follow-up.
3I (assessment)	1.00	0.00	In the current practice this is a physician task. Further, there is no assessment tool used in the current nursing practice for IBD patients.
3J (refer patients appropriately)	1.00	0.00	Study nurses and ambulatory care nurses call the physician as soon as they are aware of something. During the follow-up visit, physicians can refer patients to experts.
3K (advice line)	1.00	0.00	Advice lines would be very relevant and helpful. However, I doubt that patient would accept to call someone they do not know well. Patients do not know where they should call; therefore, they chose to call sometime a study nurse and sometime the secretary of the physician. The physicians receive about 10–20 calls and emails a day.
3L (conduct patient reviews)	0.91	0.00	Hospitalized patients would profit from an IBD expert nurse reviewing the documentation and visiting the patient on the ward.
3M (ensuring quality)	1.00	0.00	Every nurse and physician has to report on the electronic documentation system; however, this is applicable only for in-patients.
Sum score	0.98	0.06	

The first row shows the categories named with the N-ECCO nomenclature with a key word respective sentence. The second row shows the relevance score and the third the current practice score. Each item was scored in view of relevance and current practice with (1 = relevant statement respectively currently followed statement; 0.5 = partially relevant statement respectively currently partially followed statement; 0 = not relevant statement respectively not currently followed statement).

Appendix 2

The Priorities Mentioned by the Experts after the Interview

At the end of the interviews the experts were asked about their priorities for future nursing care in IBD nursing at our center. They said: 'we need…	Summary
… a drop in center or at least a contact nurse for all IBD patients and all concerns. This person triages the patients and refers them to the designated health expert. This nurse must educate these patients with a unitary information/education concept.	Nurse-let drop-in IBD center
… to develop a drop in center or at least a contact nurse for all IBD patients as gateway. These nurses would replay emails, prepare prescriptions, call the patients, monitor the follow-up data and schedule appointments or checkups following the structured pathway (that has as well to be developed).	
… to develop a structured monitoring (vaccines, preventive diagnostic, regular blood drawings and checkups).	Structured follow-up
… regular visits in the ambulatory care to update the file and to early identify problems.	
… a structured follow up, with implemented advice line.	
… an advanced practice nurse proactively facilitating the interdisciplinary collaboration.	Advanced IBD nurse
… a holistic patient approach for the whole interdisciplinary team. IBD patients need to be taken seriously not only in medical but in psychosocial issues. Alternative care concept need to be developed, for example, to reduce stress.	Proactive system
… an interdisciplinary team according to ECCO	
… structured case discussions	
… to emphasize on empowerment of the patients and support in everyday life.	
… lobbying for better system factors (more rooms, especially a room for confidential assessments to respect the patient's privacy).	Patient's respect for privacy

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